University of Alberta

Dutch Perspectives on Euthanasia in the Netherlands: A Qualitative Examination of Caregivers and People with Disabilities

By

Richard E. Lucardie

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Education

in

Special Education

Department of Educational Psychology

Edmonton, Alberta
Fall 1997

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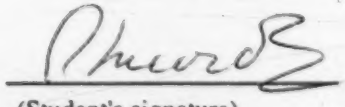

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ABSTRACT

The act of euthanasia is permissible in the Netherlands under prescribed guidelines. To get an understanding of the social realities of the practice and policy of euthanasia in the Netherlands, several qualitative studies were conducted with people who would be most affected by such a policy. Two studies are presented here. The first study examines 10 Dutch caregivers of people with disabilities. The second study examines 7 Dutch people with disabilities. Through semi-structured interviews, the experiences and perceptions of participants regarding euthanasia and the Dutch policy on euthanasia were obtained. Thematic analysis of the data revealed unanimous support for the practice and policy of euthanasia. Different rationales were used to qualify support. Abuse concerns, and suggestions for guidelines were addressed.

DEDICATION

For Dr. Dick Sobsey, for his many contributions to society, showing that one person does make a difference.

In memory of Donna Lynn Yanish Stamp, for her dignity, strength, and most importantly, her friendship. Thank you for re-introducing me to psychology. You are greatly missed.

For Lori Yanish, for making the adventure possible, and sharing it with me.

ACKNOWLEDGEMENT

This work could not have been accomplished without the support of many individuals with whom I have had the pleasure to work. Firstly, I would like to thank my advisor, Dr. Dick Sobsey, for his guidance and support throughout my Masters program, and for allowing me the freedom to explore. I would also like to thank my committee members, Dr. Jane Drummond and Dr. Eamonn Callan, for their critique of my work and for making the oral defense a very positive experience. In addition, I would like to thank Professor Johannes Reinders from the Vrije Universiteit van Amsterdam, for his participation in my oral defense and the stimulating discussion afterwards.

A special thanks goes out to the participants from the Netherlands, who gave so freely of their time and permitted me to learn about the infinite complexity of bioethical issues surrounding end of life decisions. To Elsa and Evert, hartelijk bedankte voor alles dat jullie voor ons hebben gedaan.

My experience in graduate school would not have been as pleasurable without the company and support of my fellow graduate students. To Wade Randall, thank you for your friendship and conversation during our many coffee and doughnut breaks together. Thanks as well to Dr. Madhavan Thuppal (Brother Madhavan) and Monty Nelson for keeping me laughing throughout the process. Thanks also to Shiela Mansell for sharing the office, psychological insights, and rehashing episodes of the *X-Files*. In addition, I would also like to thank Anju Anand, Tansel Erdem, Darcy Fleming, Dianne Henderson, Pat Hughes, Sukitha Kunasegaran, Yvonne Legris, Daniel Lemoine, Jolene Leps, Marya Owen, Timos Papadopoulos, Dr. Rauno Parrila, Marilyn Pottage, Gil Rutherford, and Kay Wilson.

Finally, many thanks to my family for their support in my endeavors and for staying closely in touch with both Lori and me while we were out of the country. I would particularly like to thank mam en pap, for providing us with a roof over our heads after coming back from the Netherlands and helping us get back on our feet. To Larry, Doreen, Cheryl and Gord, for Sunday dinner get togethers. To Andy and Roni for keeping our keepsakes safe and sound. To Arend and Sherry, and Carol, Dave and the boys, for their support while we were shuttling back and forth between Calgary and Edmonton. Lastly, I would like to thank Lori for her strength, courage, and unconditional support in all things I attempt to do. Your love, gentle encouragement, and sense of humour has made this experience very memorable.

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INTRODUCTION

In 1995, three qualitative studies addressing issues surrounding euthanasia were conducted in the Netherlands. Two studies which examined Dutch people's social understanding of their country's policy on euthanasia and their experiences with that policy, are reported here. These studies were conducted in unison during a five month period, and are part of a broader study which includes an examination of the experiences and perceptions of people age fifty-five years or older.

The Netherlands, the only country to date with an existing policy on euthanasia, provides an ideal setting in which to study the perceptions and experiences of people concerning this topic. Discussion on euthanasia is relevant to Canadians given the recent Special Senate Committee hearings (Senate of Canada, 1995). The Special Senate Committee was brought together to consider whether it was advisable to legalize euthanasia and assisted suicide.

The first paper presents a study of Dutch caregivers of people with disability, which was published in *Psychology and education in the 21st century: Proceedings of the 54th annual convention international council of psychologists* (Lucardie & Sobsey, 1997). Ten Dutch caregivers were interviewed concerning their perceptions and experiences with euthanasia and the policy on euthanasia.

The second paper presents a study of Dutch people with disabilities. Seven participants were interviewed concerning their perceptions and experiences with euthanasia and the Dutch policy on euthanasia.

For caregivers of people with disabilities, the issue of medical treatment concerning the end of life is a reality which they encounter through their work. For people with disabilities, their physical condition brings them closer to the issues of euthanasia and assisted suicide. In addition, interest groups representing people with disabilities in support of and against legalization of euthanasia and assisted suicide have both been vocal in this debate.

A qualitative method was used to collect the data. Semi-structured interviews were conducted with participants. Questions were open-ended with appropriate encouragement given throughout. Interviews were conducted in Dutch and audio-taped for later transcription. Transcripts were then translated into English, and thematically analyzed: Endnote Plus, a computerized database, was utilized to organize the data.

The investigator took a number of steps to ensure confidentiality and rights of subjects in these studies. These included obtaining clearance from the Ethical Review Committee at the University of Alberta, ensuring that participants were: a) given full disclosure of all benefits as well as risks associated with the study, b) informed that they

could withdraw from the study at any time with no negative effects, c) that proper informed consent was obtained in writing at the onset of the study. Furthermore, the researcher ensured that the data was kept confidential at all stages of the study.

Historical References on Euthanasia from Germany and the Netherlands

A historical reference by Burleigh (1994) examined euthanasia in Germany from 1900-1945, where the nation's policy of euthanizing those described as unproductive members of society resulted in the deaths of approximately 200,000 people with disabilities. In Germany, euthanasia was first considered for children with severe disabilities. On August 18th, 1939, the Reich Committee introduced compulsory registration by physicians and midwives of 'malformed' newborns and of children with 'idiocy' and Down Syndrome, microcephaly, hydrocephaly, physical deformities, and forms of spastic paralysis. Those registered were arranged to be admitted to pediatric clinics by parents or public health officials. In these clinics, the children died as a result of complications due to disease, starvation, or overdoses of sedatives. From its initial focus on children with severe disabilities, the German euthanasia program evolved to include adults with disabilities. Aktion T4, as this program became to be known, involved the extermination of psychiatric patients living in asylums. Eventually, the German euthanasia program evolved to include anyone who was defiant, alien, or imperfect, resulting in the Holocaust. While economic and eugenic motives were clear in the Nazi euthanasia program, the rationale of relief of suffering was frequently invoked and no doubt sincerely believed by many involved.

Since 1973, Dutch courts have examined issues concerning euthanasia. In 1973, the Regional Court in Leeuwarden oversaw a case involving a physician who administered a lethal dose of morphine to her terminally ill mother. The court concluded that a physician's duty was not to prolong life in all circumstances. In certain cases, physicians were allowed to prevent serious and irreversible suffering, even given that this action could result in shortening the patient's life. In 1984, following numerous cases of euthanasia and assisted suicide in Dutch courts, the Dutch Supreme Court clarified the legal guidelines under which the acts of euthanasia and assisted suicide could be accepted. In 1994, these guidelines were reaffirmed by the Supreme Court. These guidelines state that a patient's request for euthanasia or assisted suicide must be voluntary, competent and durable. The patient's request must be based on full information, and the patient must be in a situation of intolerable and hopeless physical or emotional suffering. In addition, no acceptable alternatives to euthanasia or assisted suicide can be left to the patient, and the physician

overseeing these cases must consult with another physician before these acts are performed (Schwartz, 1995).

The Netherlands recently discussed steps to further decriminalize the act of euthanasia (van der Leij, 1997). It is hoped that these interviews and history will contribute to furthering the discussions on euthanasia, assisted suicide, and other medical decisions concerning the ending of life in the Netherlands, and elsewhere. Awareness of the social realities of this policy may provide further guidelines as to its practice.

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Euthanasia in the Netherlands: Caregivers' Perspectives

by

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Euthanasia in the Netherlands: Caregivers' Perspectives

Introduction

The Netherlands is the only country to date which has an established policy permitting euthanasia and assisted suicide. While this policy is not law, it provides guidelines for physicians who perform such acts, and prosecution is unlikely if physicians stay within the prescribed guidelines for performing and reporting euthanasia (Dillmann & Legemaate, 1994). With countries such as Canada, the United States, and Australia currently debating the issue of such life-terminating treatments as euthanasia and assisted suicide, an examination of the acceptance of the existing policy on euthanasia may help clarify this discussion.

Perspectives on a policy of euthanasia seem to be two fold. On one side are those individuals who view a euthanasia policy as a means towards self-determination concerning end of life decisions. Supporters of such a policy feel that people have the right to chose death if they so desire, and to be assisted in dying. On the other side are those individuals who fear the "slippery slope" where the acceptance of a policy on euthanasia would lead to a gradual abatement of that policy's criteria for performing euthanasia.

The Dutch debate on euthanasia and assisted suicide has continued since 1973. On November 30, 1993, with the passing of Bill 22572, the Dutch Senate brought about changes to the Burial Act which made performing euthanasia and assisted suicide, non-prosecutable if certain guidelines were followed (Dillmann & Legemaate, 1994). This report describes a phenomenological study which was conducted to find out what people in the Netherlands think about euthanasia and the policy of euthanasia. In particular, a study of Dutch caregivers who work with people with mental retardation, multiple disabilities, or the elderly was undertaken, with attention paid to the completeness of caregivers' understanding of the Dutch guidelines on euthanasia and the way they viewed their roles and responsibilities in the application of euthanasia.

Caregivers were chosen because of their responsibility for the health and welfare of their charges, and because some elderly people, or people with mental retardation or multiple disabilities, are not able to give consent or communicate their wishes concerning medical treatment. While the Dutch policy on euthanasia is primarily being considered by people who are chronically or terminally ill, a greater application of euthanasia concerning persons who cannot give consent is being seen in the Netherlands (Pijnenborg, van der Maas, van Delden, & Looman, 1993; van der Maas, van Delden, & Pijnenborg, 1991).

In the Netherlands, euthanasia is defined as the active termination of a person's life at his or her request, by another person (Dillmann & Legemaate, 1994). Cases in the

Netherlands which are not considered acts of euthanasia include cases when medical treatment is terminated because it is deemed futile; the use of medication for alleviating pain or suffering might quicken death; and medical treatment is refused by the patient (Leenen, 1994). In 1984, criteria guidelines for euthanasia were set out by the Royal Dutch Medical Association (K.N.M.G.) stipulating that the request for euthanasia must be voluntary, competent, and durable. The request must be based on full information of the medical situation and prognosis. Unacceptable and hopeless mental or physical suffering must be exhibited with no acceptable alternatives available. The physician to whom the request is made must consult with another physician regarding the decision (Dillmann & Legemaate, 1994). The Royal Dutch Medical Association views the physician as the only competent person to perform life-terminating treatment (Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst, 1994).

The Changing View on Euthanasia in the Netherlands

The changing views on what is appropriate concerning euthanasia and assisted suicide, continue to be challenged in the Courts of Justice in the Netherlands. The move to wider application of the euthanasia and assisted-suicide policy has been noted in the Chabot case. In 1993, Dr. Chabot, a psychiatrist, was exonerated by the appeals court in Leeuwarden for not having his patient consulted by another physician when assisting in the death of 50 year old Hilly Bosscher, a severely depressed woman with no physical illness (Bayin, 1995; Hendin, 1994). The Chabot case introduced the first known case of emotional suffering as a legitimate request for assisted suicide. In a recent case, a Court of Justice in Alkmaar acquitted Dr. Henk Prins for performing euthanasia on an infant with hydrocephalus, spina bifida, and brain damage. The request for euthanasia was made by the infant's parents (Huibers, 1995). Their surrogate request for euthanasia on behalf of their child was deemed appropriate.

Summary of the Literature Review

Statistics from the Netherlands indicate that the Royal Dutch Medical Association's criteria guidelines for performing euthanasia are not being adhered to in all cases. While euthanasia in the Netherlands is primarily being considered by people who are chronically or terminally ill, the Prins case and a study by van der Maas, van Delden, and Pijnenborg (1991) indicate that euthanasia frequently occurs regardless of the patient's requests for this. These findings are also observed in countries other than the Netherlands where the termination of medical treatment is initiated against the expressed wishes of the patient or surrogate. It appears that decisions are being made concerning persons who are chronically

or terminally ill, who are unable to give consent to euthanasia or to the termination of medical treatment, or who are not asked to be involved in the decision making process (Asch, Hansen-Flaschen, & Lanken, 1995). Huang and Emanuel (1995) noted that physicians were more likely to consider a patient's autonomy in requesting assistance in dying when a patient reported being in extreme physical pain. Stevens and Hassan (1994) observed that there is support for euthanasia by health care workers, although the decisions concerning the management of death is based primarily on moral and ethical grounds rather than legal grounds. Even in some hypothetical case scenerios concerning the withdrawal of life support, opposing extremes of medical intervention were choosen by health care workers (Cook et al., 1995).

Methods

Nine of the 10 caregivers interviewed in this study were female. They ranged in age from mid twenties to early fifties. Six caregivers came from a group home for the mildly to moderately mentally retarded. One caregiver worked in a care facility for the elderly, and three caregivers worked in a care facility for people with multiple disabilities. One caregiver was a physician, two were directors of their respective centres, two were team leaders in their departments and five worked as full time caregivers. Caregivers were recruited from the telephone book under the listings for appropriate centres. The centres were located in two towns in the province of Zuid Holland. Experience with care giving ranged from several years to more than twenty years experience.

All semistructured interviews were conducted in Dutch and were audiotaped for later transcription. Interviews were of approximately 30 minutes duration with some lasting 50 minutes or more. Caregivers were interviewed using standardized questions concerning their opinion and experience with euthanasia, the Dutch policy on euthanasia, and the effects of this policy on their lives and the lives of the people they cared for.

As authors of this article, it is important for us to acknowledge our own position on euthanasia and assisted suicide, particularly as they are practiced in the Netherlands. While we do not feel that assisted suicide and euthanasia are inherently wrong in every case, we are extremely concerned about the potential for error and abuse. We believe that any law or policy that allows these practices should be accompanied by the strictest of safeguards and consider the current Dutch safeguards to be inadequate both in design and implementation.

Results

The results of the study can be categorized into several themes. While caregivers responded to questions with reference to euthanasia or the policy of euthanasia, many

caregivers also included life-terminating acts without explicit request of patients in their discussion of euthanasia.

Quality of Life All caregivers justified their acceptance of euthanasia based on a person's quality of life. "If you are in so much pain and you cannot enjoy anything anymore, I think that you would rather be gone from this earth."

Autonomy Most caregivers felt it important that the rights of the individual to decide over their own life were respected. "Respect for your fellow man. Just the respect to be able to decide about yourself and your own life. That is what euthanasia is for me."

Mixed Argument For many caregivers, a rationale for euthanasia based on a combination of quality of life and autonomy rationale was observed. It is reasoned that a person who is suffering has a right to choose death.

> I feel that sometimes there are moments where you think, is this life still worth living, and if you can clearly indicate that, "well, I do not want to go on any further" then I think (pause) Then I think that it is very respectful to be able to let someone go.

A Dignified Death Some caregivers also rationalized euthanasia or life-terminating acts without specific request as a means by which a person is able to die in a dignified manner, hence making these acts more acceptable.

> ...the advantage of something like this is, I think, that if you make the choice that hey, this [suffering] can be stopped, then I would think (pause) Death. I actually find it a dignified manner, because your life is your own.

Ambivalent Attitudes Some caregivers stated their support for euthanasia but qualified their support with both concern and discomfort.

> I cannot say just one thing in general about it. I cannot say that in this situation I think that it should be allowed and in the other situation it should not, or that it should always be allowed if a person asks for it themselves. No. I do not think so. No. Each case should be very carefully examined.

No Direct Involvement None of the caregivers in this study mentioned any direct involvement with any form of euthanasia or assisted suicide as per the Dutch government's definitions. This was most reflective of the people these caregivers cared for, most of whom could not verbalize such a request.

> ...because here we are working with people who are not capable of making their wishes known. Our people cannot ask for it themselves, and they do not do that either, and so, it is not at all allowed here. You are not allowed to actively end someone's life, because he has never asked for it himself...

Life-Terminating Acts Some caregivers did comment on cases involving residents for whom life-sustaining treatment was terminated or the use of morphine was used to treat pain resulting in premature death. "Let's say that what in the past was called passive euthanasia, that does occur here very often..."

In these cases, caregivers felt that decisions had to be made with a great deal of consideration. Most often, these decisions concerning the possibility of an action which would result in the premature death of a resident were made by substitute decision makers. "So it is often a decision which you, let's say, make together with parents, with group leaders, with a physician, and then often still with the service of a spiritual guide like a clergyman or so..."

Diminished Quality of Life Upon speculation on substitute decision making in situations involving people who could not verbalize a request for euthanasia or in actual instances involving residents, a diminished quality of life was mentioned as a reason for discussing or carrying out an action which could result in the premature death of a residents. "Yeah, that is purely what you observe from someone, the pleasure in life. Yeah, does someone feel comfortable for example? Does someone have pain or not?"

Futility and Natural Death Rationale for life-terminating acts based on the futility of further treatment or the view that the person would have died anyway if nature was allowed to take its course, were given by caregivers when speculating on substitute decision-making situations or when talking about residents, in particular, a boy of nine years who had a metabolic disease.

> But actually, if he could have talked, he might have wanted to have said, 'I want (pause) Eh (pause) Yeah, I want to die' three years earlier. Now, two years earlier I

> think, because you could see him suffering. I mean, he had the diaper on and if you had to change him, then he screamed because of the pain. Yeah, he was just constantly crying on the ward, and he was so sad, and you also knew that he would still pass away.

Who is Helped? Caregivers were asked to respond to the question about who was helped by euthanasia or by the policy of euthanasia. In many cases, caregivers responded that, "The patients who really want euthanasia are helped by it."

Burden on Family or Surroundings Some caregivers rationalized that besides the person themselves, their family and surroundings would also benefit by them having euthanasia performed.

> The person's surroundings could be helped by it, because naturally it is (pause) Well, I would think that it would be terrible if, for example, people who are in a bad situation and suffering terribly (pause) I would find that terrible.

Benefit to the family was also noted in cases concerning life-terminating acts and life expectancy changes involving residents. In these cases, it is noted that the responsibility of caring for someone who is ill can be difficult.

> Well right now everyone is just resuscitated, whether there is consent or not. While maybe afterwards it would seem that the parents say, "yes, but we actually did not want that."... Yeah, it has always been said that someone will only live to be 10 years old, for example, and now you suddenly say that yeah, I now maybe have to go to [name of resident facility] until someone is 40 years old. Now that of course is naturally very hard to hear for some parents.

Where an action resulted in the premature death of a resident, some caregivers felt that residents were helped in the sense that their suffering was over. Others felt that they themselves or the family were helped, with the knowledge that they made the right decision which ended a resident's suffering. For some, the knowledge that they helped end someone's suffering justified their decision. "...at the group home where I worked before, we actually applied a form of passive euthanasia and I have the feeling that we helped the resident with that. You need that, otherwise you haven't made a good choice, I think."

Advantages and Disadvantages During the interview, caregivers were asked their opinion on what they thought the advantages and disadvantages of euthanasia and the policy of euthanasia were. Caregivers felt that it was advantageous that people could decide over their own lives, and were able to be assisted with death. Some felt that it was advantageous that there were guidelines within the policy which placed boundaries on what was and was not allowed. Some caregivers felt it advantageous that the policy protected physicians, that one could not be prosecuted or investigated if one abided by the guidelines which were set out. One caregiver summed the advantages up this way:

> An advantage is that everything goes very well, that everything is thought out. That the decision is not emotional but that for the (pause) Also that you cannot be prosecuted for that. That an investigation will not be initiated as soon as I, as health care worker, perform euthanasia on someone, if that was requested on paper. That it cannot be prosecuted.

While one caregiver felt that there were no disadvantages to having a policy on euthanasia, others felt that as a result of having such a policy, people may give up on life sooner. "That they sometimes grab for it (euthanasia) like it is some sort of salvation remedy, as long as that is then the end..."

Policy Comprehension Unfamiliarity with the policy on euthanasia was observed for some caregivers when questioned about the influence of the policy on them or the residents.

> I think that, as you see it with the policy (pause) yeah, how it is now regulated, euthanasia (pause) Yeah, I think (pause) I find it really difficult. Especially because you (pause) It is such a difficult subject. It is so complex.

Other caregivers were a little more clear with the guidelines. "You know where you stand and what your options are. That is what I find with this policy."

Concerns with the Policy When asked what they thought about the Dutch policy on euthanasia, some caregivers voiced concerns. "Well, I think that you have to be very careful with it. It should also not become too easy, and then the question is, who decides about that?"

Abuse Concerns Some caregivers voiced concerns about the potential for abuse regarding euthanasia and the policy of euthanasia. "Yeah, it can easily be abused... I think that it is another possibility."

Other abuse concerns addressed situations involving residents and life-sustaining treatment and do-not-resuscitate orders.

> Yeah, that in every situation you have decided to resuscitate, that I may think that in a certain situation that yeah, this resident is already so sick, there is already so much going on with him, I find that it is meaningless to resuscitate that person, and that person actually does not want it.

Safeguards Throughout the interviews, caregivers voiced their opinions about conditions which they felt, needed to be met when requesting euthanasia or in cases of life-terminating acts. Additional suggestions which caregivers felt needed to be addressed to prevent potential errors or abuse when requesting euthanasia focused on the decision making process.

> I think, yeah, the moment that it is indeed too easily grabbed for and not thought about enough and talked about with each other, and that it becomes a too easily made decision. Well later you can regret that. Yeah, and then you cannot do anything about it.

Addressing the issue of life-terminating treatment concerning the residents, caregivers felt that safeguards needed to be in place when making group decisions.

> ...it has to be very carefully thought about and that certainly all parties involved are not forced into it. That they can also all stand behind it. As soon as there is someone who cannot be in agreement with it, then I think that you cannot just decide with the majority.

Discussion

Limited or informal knowledge At first glance, one of the most surprising findings from these interviews is the apparent lack of formal knowledge about Dutch euthanasia laws and practices. While the official Dutch legal definition of euthanasia excludes life-terminating acts without explicit request, most caregivers did not appear to make this

distinction. By definition, the termination of life support is not considered to be a form of euthanasia under Dutch law. However, caregivers typically perceived termination of life support as a form of euthanasia.

Caregivers make a distinction between self-determined request and a surrogate request for euthanasia, but according to the official definition, a surrogate cannot make a request for euthanasia on behalf of someone else. For most interviewees, their understanding of euthanasia was clearly different from those discussed by Dutch legislators, lawyers, or bioethicists. This apparent discrepancy, however, should not be viewed as a lack of knowledge about the phenomenon of euthanasia. It more likely represents the understanding of the social realities of euthanasia as actually practiced in the Netherlands as opposed to the more abstract legal and philosophical concept that appears in academic journals and court documents. In fact, the evolution of law and bioethical discussion in the Netherlands is toward the understanding of phenomena expressed by the caregivers in this study. For example, in the widely discussed 1995 Dutch court ruling in Alkmaar involving Dr. Henk Prins, a surrogate request for euthanasia was allowed, apparently making the official definition of euthanasia, which excludes such requests, obsolete. Similarly, the revelation of 1,000 cases of nonvoluntary euthanasia reported in 1990 and 1991 along with the 2,700 cases of voluntary euthanasia and assisted suicide were generally accepted as part of a continuum of euthanasia related phenomena (van der Maas, van Delden, & Pijnenborg, 1991).

General support The caregivers interviewed in the study voiced general support for the practice of euthanasia. They believed that this practice was typically beneficial to the patients who requested them for themselves. The primary reasons given for caregivers' acceptance of the practices of euthanasia was related to issues of quality of life. A smaller number indicated that autonomy was their primary reason for acceptance. Many cited both autonomy and quality of life in a manner suggesting that autonomy was contingent on quality of life (i.e., If an individual's quality of life is poor, then he or she should be allowed to chose). Those presenting these mixed arguments seemed unaware or unconcerned about the limitations placed on autonomy by quality of life arguments. This apparent limitation is reflected in actual practice. The Remmelink report that shows 2,300 cases of active euthanasia and 400 cases of assisted suicide for 1991 also indicates 7,000 requests that were refused and 1,000 nonvoluntary cases. While in 25% of these cases, people asked for, or at least consented to have their lives ended, 75% were not given a choice. Either their autonomy was denied by ending their lives without consulting them (9%), or their autonomy was denied by denying their request to die (65%). Even in the

25% of these cases involving patients who chose or consented to die, no data is available regarding who initiated the topic or whether undue influence might have been part of the decision. Some data is available suggesting that in most of the 25% of cases where patients requested or consented to die, that procedural safeguards were not followed. For example, many were reported as natural deaths, many lacked consultation with a second physician, and many did not exhaust treatment alternatives (van der Wal, et al., 1992). Thus, the 25% figure represents the most optimistic estimate figure of autonomy available.

Those advocating for euthanasia acknowledge the procedural violations, but argue that these are details and the general intents of killing only those who wish to die and of killing only for the benefit of the patient remain intact. Whether or not this degree of faith in the system is well justified, it was shared by the caregivers in this study. While a minority of caregivers mentioned the potential for abuse of the practice, it was not a major consideration even for those who mentioned it.

While the right of the individual to choose was mentioned frequently, futility and suffering were more frequently used to explain the appropriateness of specific cases. This along with the fact that autonomy was often described as conditional on futility and suffering suggests that deteriorating quality of life may be a more important criterion than autonomy. It appeared that these caregivers felt more comfortable with ending the life of someone who was truly suffering but had not asked to die than with ending the life of someone who was clearly asking to die but was not judged to be suffering unbearably.

Ambivalence While general support for the practice of euthanasia was clear, many of the caregivers interviewed showed some ambivalence toward the practice. In spite of their general support, caregivers voiced some concerns about the way the practice was implemented, that primarily focused on the uncertainties of the decision making process. Although they felt that termination of life was appropriate in some circumstances, they often had difficulty deciding exactly what those circumstances were. They also indicated worries about imperfections in the system. For example, one voiced concerns that an individual might make an advanced directive for euthanasia under prespecified conditions, but would want to remain alive when those actual conditions were encountered, and the lack the ability or opportunity to communicate the new decision.

Conclusion

The caregivers interviewed in this study described euthanasia as a social reality in the Netherlands. Most were only partially aware of official legal and procedural information. In spite of some concerns about how these practices are applied in specific cases, they generally supported euthanasia. There was some lack of clarity about their

reasons for supporting the practice. An autonomous right to choose one's own destiny was a frequent reason cited, but deterioration of quality of life was most often mentioned and was associated with fewer limitations and conflicts. Most analyses of the practice of euthanasia in the Netherlands in professional literature is based on official definitions, guidelines and protocols. This study suggests the need for more reseach regarding actual practices and social realities.

As authors of this article, we wondered to what extent these caregivers would share our concerns about inadequate safeguards. While some of the caregivers did voice concerns about the potential for errors or abuse, these were only minor concerns for those who mentioned them, and others did not mention them at all. This might be reflective of the setting in which most caregivers were working, where euthanasia was not an issue because their charges could not communicate or comprehend a request for euthanasia or assisted suicide.

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Euthanasia in the Netherlands: A Qualitative Study of People with Disabilities

by

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Introduction

Since 1973, the Netherlands has debated the issues of euthanasia and assisted suicide. Both social and legal tenets of this debate have contributed to the passing of Bill 22572 in 1993, by the Dutch Senate, which allows for the practice of euthanasia and assisted suicide within prescribed guidelines (Dillmann & Legemaate, 1994). Physicians working outside these guidelines are liable to prosecution under Dutch Law. Other countries such as Canada, the United States, and Australia, have also examined possible acceptance of these practices. On February 23, 1994, a Canadian Special Senate Committee voted by a narrow margin that both nonvoluntary and voluntary euthanasia remain criminal offenses under the Criminal Code of Canada. The Committee did recommend amendments to the Criminal Code to allow for greater leniency in sentencing in nonvoluntary euthanasia cases provided that essential elements of compassion or mercy were evident (Senate of Canada, 1995). In November 1994, voters in the State of Oregon passed a physician-assisted suicide law. However, the law's implementation was blocked by a US. District Judge due to questions concerning its constitutionality (Shapiro, 1994). In 1995, the Northern Territories, Australia, passed the Rights of the Terminally Ill law allowing physician assisted suicide (Cole-Adams, 1995). With the ongoing debate on euthanasia and assisted suicide, it is important to examine the social realities of euthanasia in the Netherlands since it is the only country to date with a working policy. Insight into the social realities of euthanasia may contribute to furthering our understanding of this subject and continued development of its discussion.

To gain insight into the social realities of euthanasia, a study was conducted examining the experiences and views of people with disabilities in the Netherlands. In the Netherlands, euthanasia and assisted suicide are primarily performed on patients who are chronically or terminally ill due to cancer, cardiovascular disease, disease of the nervous system, pulmonary disease, or mental disorder (van der Maas, van Delden, & Pijnenborg, 1992; van der Wal, van Eijk, Leenen, & Spreeuwenberg, 1991).

Definition of Euthanasia

In the Netherlands, euthanasia is defined as the active termination of a person's life at his or her request, by another person (Dillmann & Legemaate, 1994). Leenen (1994) notes that cases in the Netherlands which are not considered acts of euthanasia include those where medical treatment is terminated because treatment is deemed to be of no use;

cases where the use of medication for alleviating pain and suffering might bring about a quicker death; and the refusal of medical treatment by the patient. In 1984, the Royal Dutch Medical Association (K.N.M.G.) set out guidelines for the performance of euthanasia by a physician. It requires the issue of a request made by the person who wants to be euthanized. The request must be competent, durable, and be based on full medical information concerning the patient's prognosis. Mental or physical suffering which is deemed to be unacceptable and hopeless must be exhibited. In addition, the patient must have no acceptable alternatives for treatment left. Lastly, a second physician must be consulted (Dillman & Legemaate, 1994). Under Article 293 of the Criminal Code, a person performing euthanasia in the Netherlands could receive up to 12 years in jail or a category 5 fine which could be up to $60,000 in U.S. dollars (Weijer, 1995). However, since approximately 1985, this offense cannot be prosecuted in cases which meet current procedural guidelines (Legemaate, 1994).

Recent History of Euthanasia in Dutch Courts of Justice

Leenen (1989) has noted frequent disregard of the guidelines for euthanasia in the Netherlands. For example, in 1987, a nursing assistant performed euthanasia on a patient with mental retardation and deteriorating health. The nursing assistant was convicted of murder, and was sentenced to a year in jail, because the patient had not requested euthanasia. In 1988, a Court of Justice in Almelo found a neurologist guilty of performing euthanasia on a patient without the patient's request. The neurologist had ordered a nurse to inject the patient without giving information as to the reasons for the injection, and had made a false declaration of death. In this same year, the court disallowed nurses from terminating life on their own initiative. The court rejected the argument of job related psychic stress as a reason for nurses performing euthanasia. In 1993, Dr. Chabot, a psychiatrist, was found guilty by a Court of Justice in Assen, for not having another physician consult his patient when assisting in the death of 50 year old Hilly Bosscher. Bosscher was a severely depressed woman with no physical illness. However, in September of that year, Chabot was exonerated by the appeals court in Leeuwarden (Hendin, 1994). In a recent case, a Court of Justice in Alkmaar acquitted gynecologist Henk Prins for performing euthanasia on an infant with hydrocephalus, spina bifida, and brain damage. The request for euthanasia was made by the infant's parents (Huibers, 1995). The changing views on what is appropriate concerning euthanasia and assisted suicide, continues to be challenged in the Courts of Justice in the Netherlands. The Chabot and Prins cases illustrate the movement to a wider application of the policy.

Statistics of Euthanasia in the Netherlands

In 1990, a study was commissioned by the Remmelink Committee to determine the extent of the practice of euthanasia and the nature in which it was carried out. The findings were published in 1991, and resulted in the Remmelink Report. The study, which was conducted by van der Maas and associates, reported that 1.8% (2300 deaths) of annual deaths (128, 786 deaths) in 1990 in the Netherlands resulted from euthanasia. Assisted suicide accounted for 0.3% (400 deaths), and life terminating acts without specific requests accounted for 0.8% (1000 deaths) of annual deaths in the Netherlands. In approximately 2.0% (2576 deaths) of annual deaths, it could not be distinguished whether euthanasia, life terminating acts without specific requests, or alleviation of pain and symptoms with opiods resulting in shortening life, were involved (van der Maas, van Delden, Pijnenborg, & Looman, 1991). Van der Wal, van Eijk, Leenen and Spreeuwenberg (1992a) reported that about 5000 requests per annum were made for euthanasia or assisted suicide, with 40% of serious requests carried out. In addition, van der Wal, van Eijk, Leenen and Spreeuwenberg (1992b) found that doctors (n=186) reported that the most common reason patients gave for requesting euthanasia or assisted suicide was futile suffering (56%). Additional reasons most commonly reported by patients were fear or avoidance of humiliation (46%), unbearable suffering (42%), and pain (35%).

From 1981 to 1992, the reported cases of euthanasia have steadily increased, while in comparison, prosecutions have declined, with most resulting in dismissals (van der Wal & Dillmann, 1994). The increase in reporting might reflect the clearer guidelines which physicians must follow when performing euthanasia. It might also be reflective of the leniency in prosecution of physicians. While the reporting of cases of euthanasia is on the increase, approximately 70 percent are still misreported as declarations of natural death (Kimsma & Ciesielski-Carlucci, 1993).

Attitudes of People with Disabilities, Chronic Illness, and Terminal Illness

Some recent studies have examined the attitudes of people with disabilities and terminally ill patients concerning end of life decisions. Schneiderman, Kronick, Kaplan, Anderson, and Langer (1994) studied the attitudes of seriously ill patients in the United States toward treatment that involved high costs and burdens on others. Both cancer and AIDS patients who were identified by their physicians as having only a 50% chance of living for another 5 years, participated in the study. The first question patients were asked examined their desire to live if the outcome of medical treatment left them completely and permanently dependent on family or friends for their daily care. The second question examined how much personal life savings a patient would be willing to spend if the

outcome of medical treatment left them completely and permanently dependent on others. Of the 132 patients who responded to the first question, 28% stated that they would not want to live, in a state of complete and permanent dependency on others. Sixty percent stated that they would want to live less than a month under those conditions. Only 14% of respondents stated that they would prefer to live as long as possible under those conditions. With regards to how much of their life's saving they would be willing to spend, 27% of the 128 patients who responded to this question stated that they would not be willing to spend any of their life's savings. Sixty seven percent of patients stated that they would only be willing to spend 50% or less of their savings. Twenty three percent of patients were willing to spend all of their savings.

Shortcomings of this study were noted by the authors. They surmised that greater detail might have been obtained if responses were gathered through personal interviews rather than written questionnaires. Another shortcoming stems from the hypothetical nature of the questions. Euthanasia and assisted suicide are currently not lawful in the United States.

A related body of studies has examined the perceptions of quality of life of people with physical disabilities. Social abilities appear to be related to a perception of a good quality of life more so than are physical disabilities. One may surmise that the level of isolation a person feels from the social sphere may have an impact on decisions to continue treatment and living. Osberg, McGinnis, DeJong, and Seward (1987), examined predictors of life satisfaction and quality of life among 97 moderate to severely physically disabled elderly adults. All participants were post rehabilitation patients from 3 centres in Boston, Massachusetts, and ranged in age from 60 to 95 years. Dependent variables were measured by examining responses to 4 variables which measured quality of life such as general satisfaction with life; subjective health rating compared to age; examination of social relationships; and examination of financial situation. Independent measures were obtained by having participants numerically scale their responses to a self administered questionnaire. The questionnaire included the Barthel Index, which measured functional capacity such as self care and mobility skills representing independent activities found in daily living. In addition, six variables were used to measure activity. These consisted of social activities outside the home; telephone or visits by nonhousehold persons; participation in formal organizations; providing care for others; executing household duties; and time spent on academic activities. Additional information was obtained from medical records, telephone administered checklists, and interviews with caregivers serving the participants. The authors found that functional capacity, as measured by the Barthel Index, and activity were the most prominent and significant indicators of quality of life for both

men and women. Hence, those participants who were more active and obtained higher levels of functioning reported greater quality of life.

Stensman (1985), compared the quality of life and evaluation of functions of people with severe impaired mobility and nondisabled people in Sweden. Thirty six subjects with disabilities were matched with controls. The majority of persons with disabilities were diagnosed with cerebral palsy (13), spinal cord injury with quadriplegia (6), multiple sclerosis (5), hereditary ataxias (4), and other spinal disorders (4). Subjects ranged in age from 24 to 52 years. Subjects were asked to rank order from 0 to 10, 30 different abilities consisting of both physical and mental functioning, interpersonal and social relationships, and overall quality of life. The authors found no differences between the two groups with regards to quality of life. For the people with disabilities, social ability was felt to be of greater importance than for controls. Motor functions were felt to be of greater importance for controls than for persons with disabilities.

Rudick, et al. (1992) compared the quality of life among patients with chronic medical diseases. Patients with inflammatory bowel disease (n=162), rheumatoid arthritis (n=75), and multiple sclerosis (68) were questioned using the Farmer Quality of Life Index. The index consists of 47 standardized questions which are grouped into clusters consisting of functional and economic subscale; social and recreational subscale; affect and life in general subscale; and medical problems subscale. Patients had been diagnosed with their specific disorders for at least 10 years. While age and duration of the chronic medical disease did not significantly affect quality of life, having multiple sclerosis was found to impact quality of life more significantly than either inflammatory bowel disease or rheumatoid arthritis. It is theorized that multiple health problems associated with multiple sclerosis may attribute to this finding. Gender was also found to be an indicator of quality of life with women scoring more poorly than men. However, the authors concluded that disease type influenced quality of life more than gender.

Chochinov et al. (1995) conducted a study of 200 terminally ill patients to investigate their desire for death, the pervasiveness of this desire over time, and its clinical association with psychiatric disorders. Through semistructured interviews and the completion of the Beck Depression Inventory, the researchers found that occasional death wishes were voiced by 44.5 % of patients, with serious, pervasive death wishes voiced by 8.5% of patients. Depression in patients was most signifantly correlated with the desire for death. Pain and low family support also correlated with death wishes. Appoximately 60% of those patients who desired death were diagnosed with depression. This desire decreased over time.

Summary of Literature Review

The literature seems to indicate that for a majority of people with terminal illness such as cancer or AIDS, death would be preferred over living in a permanent state of dependancy. For severely physically disabled elderly adults, quality of life is a measure of functional capacity and activity, with greater quality of life reported by those who are more active and have greater functional capacity. These findings are also true for patients with chronic medical diseases. In addition, the literature indicates that there are no differences in the quality of life for people with severly impaired mobility when compaired to controls, and that the desire for death among the terminally ill are often associated with clinical depression.

Methods

In the present study, purposeful sampling focused on people with physical disabilities in the Netherlands. Research participants were recruited through the telephone book under the listings for appropriate societies which assist people with disabilities. These societies included a multiple sclerosis society and a society for people with physical disabilities. The representatives for the societies were contacted and informed about the study. A request was made for volunteers who were willing to be interviewed about euthanasia and the Dutch policy of euthanasia. The representatives located participants who were willing to be interviewed and obtained their permission to be contacted by the researcher. The researcher was given the names and phone numbers of participants and initiated contact with them. The research study was explained to participants over the phone and their agreement to be interviewed was obtained, upon which, a meeting was scheduled. Prior to beginning the interview, participants were given an introduction to read which explained the interviewer's background as a research assistant and the reason for this study. Participants were asked if they would consent to be interviewed. All participants gave their consent. All interviews were conducted in Dutch and were audio taped for later transcription. Interviews lasted approximately 30 to 60 minutes duration. All interviews were held in private, at the participant's residence or at a community hall. The interview was semistructured, with questions pertaining to participants' opinion and experiences with euthanasia, the Dutch policy on euthanasia, the influence of the media, and the role of religion in peoples' willingness to discuss euthanasia. Participants were allowed to discontinue with the interview at any time, or omit questions which they found uncomfortable. None who participated chose to do so. Interviews were transcribed in Dutch, and then translated into English. Thematic analysis was conducted on the data and is presented in the results section of this paper.

Participants

Four women and three men agreed to be interviewed for this study. One women in her early thirties has had rheumatoid arthritis for approximately five years and requires the use of a wheelchair to move around. She has had to quit her job due to her limited mobility. One woman in her early fifties has hemipalegia due to a brain hemorrhage ten years earlier. She requires the use of a electric wheel chair when outside, but is able to move about inside her home without it. One woman in her early twenties has been visually impaired since birth and requires the use of a cane. Two of the participants, a woman in her early forties and a man in his middle twenties, both have multiple sclerosis. The woman has had MS for five years and has reduced mobility as a result. She had to quit her job due to her limited mobility. The man has full mobility and is working and studying. He has had MS for approximately nine years. One man age sixty, has a congenital orthopedic disorder requiring the use of a cane to walk around. He is currently retired. One man in his early seventies, has partial paralysis in all four limbs due to a brain hemorrhage. He uses an electric wheelchair for mobility. Participants are not receiving home nursing care. They live in their own homes in several towns in the province of Zuid Holland.

As author of this article, it is important to acknowledge my own position on euthanasia and assisted suicide, particularly as they are practiced in the Netherlands. While I feel that these practices are not inherently wrong, I find it difficult to conceive of a policy or law concerning these acts which completely exclude the possibility of potential error or abuse. Having an established policy for euthanasia and assisted suicide in the Netherlands, the strictest safeguards should be in place for its practice. The literature has shown that this is not presently the case.

With this study, I expected to encounter greater opposition to, and concern with the Dutch policy on euthanasia based on its potential for error and abuse. The findings will show that while abuse was a concern for some, participants' general support for the practice outweighed this concern. I also expected participants to have greater familiarity with the findings from the van der Maas, and van der Wal studies concerning euthanasia and other medical decisions concerning the end of life. This familiarity with the findings was not encountered.

Results

The results of this study will be discussed in terms of themes which were extracted from the responses given to specific questions in a semistructured interview. The results are presented below.

Quality of Life Participants unanimously supported euthanasia, but offered different rationales for their support. All participants felt that euthanasia was acceptable in certain situation involving diminished quality of life based on suffering.

> It is still consciously choosing for a shorter road of suffering.

> Needless suffering. ...If you are laying there, and you're dying of pain and eh (pause) Well, why does that have to be?

Autonomy Most participants felt it important that a person had the right to self-determination when deciding over their own life.

> I feel that everyone should be able to decide that for themselves... (That) I may decide when I want out.

> The point is, when the person who is suppose to go through it, comes to the point that he says, "I do not want to live anymore." Well, I am a advocate for that.

Mixed Argument The mixed argument is based in part on quality of life and autonomy. Most participants reasoned that a person who is suffering has a right to choose death.

> Yes. It happened last year and eh (pause) ...He had marrow cancer in his back... His breathing started to get jerky and then he said, "give me an overdose." Well, he did not feel like it anymore. Now, then I say that this is fine.

This mixed argument was also used by one participant who was not fully supportive of euthanasia, but who could see that in certain circumstances, it could be acceptable.

> Yeah, I am against it, but there are enough people who are suffering enough from disease or so, and yeah, I would not say that you have to do it, or you should not do it, but that it is then left up to them. They have their own will, so eh (pause) that at a given moment, that it is possible.

Futility and Natural Death For most participants, situations when further medical treatment would not benefit a person or when a person would die a natural death if nature was allowed to take its course were acceptable situations for the application of euthanasia.

> ...if you get cancer or AIDS or so (pause) I don't relate it so much to the situation which I am in right now, but just a possible future. I feel that it should be possible.

> ...and I had a friend who had cancer, bone cancer, and that goes really quickly with a lot of pain. Then I can imagine, if you experience that, that you really don't see anything positive anymore. It is terrible. Then I feel that it is okay. Yes, if you're that far along, and then I don't know if there is any hope. All you can do is pray, I think.

For one participant, the feeling of futility of further medical treatment was something which this participant had experienced while working as a nurse.

> I had an experience during my time in the hospital [with] people who had terminal cancer and who we were still obligated, as nurses, to resuscitate during a cardiac arrest. Now I find that so wrong. I'm thinking, that body is indicating what it is ready for, why should I then jump on top of it and resuscitate? Just let it go.

Personhood Some participants rationalized that for people who were no longer able to fully function as human beings, that euthanasia would be an acceptable alternative, if they so requested it for themselves.

> ...thus if you are not dead yet and you are lying there doing nothing, that you say, "darn it, this in not living" then I say, well, get that syringe or that pill.

For some rationales based on personhood, participants did not specify whether the request for euthanasia was made by the individual themselves.

> Someone who is laying there on a bed doing nothing, who is elderly, who can never be anything anymore, then I am not against it if they were to help that person...

While in one case, it was assumed that self-determination was not a determining factor when it concerned a person or child who, it was felt, was no longer be able to fully function as a human being.

> If, for example, you had a maimed infant or a comatose patient, yes, I think that you should be able to intervene.

A Dignified Death For some participants, euthanasia is a means by which a person is able to die in a dignified manner.

> Yes, that is the point. To take away the unbearability of the last couple of hours or days. That you can pass away with dignity. I find that important.

Existing Possibility of Euthanasia For some participants, the existence of the possibility to request euthanasia is important, and particularly that this possibility existes not just for people with physical pain.

> Yes. I think that it should be possible. Yes, I am a very big advocate for this. ...I feel that it should be possible for both physical suffering as well as psychological suffering.

> But also people who say, "well son, I am not sick, and I am not in a terminal phase, but I still want to get out." That has to (pause) [That] should be possible.

Some participants felt that euthanasia was preferable to dependency. These participants felt reassured that by having an option of choosing for euthanasia they would not have to be dependent on anyone for their care.

> Let's say that in a few years, that I would not be able to speak. That communication would not be possible for me anymore. Dependent, obligingly dependent on a third party. Then I would say, "it is not necessary anymore". That is what I say now, and only the idea that I (pause) when I become completely dependent on a third party, and I can say, "now I'm getting out", then it is for me (pause) Yeah, a lovely (pause) I find that peaceful.

Burden of Disability For two of the participants with paralysis, becoming suddenly disabled because of brain hemorrhages brought with it additional burdens which in some cases made living life less enjoyable.

> ...it demands a lot of strength to cope with becoming disabled from one moment to the next, and well, then you still come across things which you cannot do, and that can really eat at you, and then (pause) or that your family reacts irritable towards you, or that they say, "geez, hurry up", or eh (pause) and you can't, and that asks a lot of you to cope with that, and then when you have had such a rotten day, yeah then you ask yourself, why am I still alive?
>
> Do you know that I have had therapy now for four and a half years in a row. That also gets to you. You also get tired of that.

Although for these two people, the desire to live, outweighed the limitations they encountered resulting from their disabilities. As one participant explains:

> If I have had a bad day, then sometimes, at night when we go to bed, I have said to my husband, "now I only hope for one thing, that tomorrow morning I don't wake up." But now I have recovered so much again and now I think, "what were you thinking?" ...Yeah, if you have had a good day, then (pause) and then the sun shines or you see a little plant growing again and then you think, well, I can still enjoy all that.

Who is Helped? In response to the question about who was helped by euthanasia or by the policy of euthanasia, many participants felt that the people who requested this for themselves, and people who were suffering were helped.

> Yes, and who has been helped the most, I think that those are the people who were allowed to die.
>
> People who are really suffering, they are then helped by it.

Some participants felt that the family would also be helped by the act of euthanasia with the knowledge that their family member was not suffering anymore.

> The relatives will feel a lot of sorrow, but maybe less so if they see how someone (pause) My mother died of cancer... She was so thin, so emaciated, and I never want to experience that again.

> ...but also the relatives, they are also helped, because they are suffering just as much. Certainly if you are married and your husband or wife is terribly sick, then you suffer just as much naturally.

Who Suffers? When questioned about who they thought suffered because of euthanasia being performed, some participants felt that the relatives of the euthanized person suffered.

> That such a person, who would want to (pause) [have euthanasia] for himself, but the others have not come to accept it yet. That the person who takes that step (pause) and yeah, because you can of course also view euthanasia as a sort of suicide. ...but then, there are still people who suffer because of that. Then certainly his circle [of friends], patients, people who care about him, his mother, thus also his wife and children.

One participant felt that the family suffered because euthanasia was not performed. Hence the family had to be witness to the suffering endured by the 75 year old patient who had cancer.

> My father in-law, he had a very strong character, a really fine man also, but up to the end, while the chemotherapist (pause) Eventually he ended up in intensive care, and the end was there, and it came, and that was not such a easy farewell for the whole family, my wife, her sisters, her brother and I.

Advantages During the interview, participants were asked their opinion on what they thought the advantages of euthanasia and the policy of euthanasia were. The majority of participants felt that the greatest advantage of euthanasia or of having a policy on euthanasia was that people could decide for themselves when to end their life, if they felt that they had suffered enough.

> I may decide when I want out. That I do not have to be afraid to ever be in pain, or (pause) Yeah, for one person their pain sensitivity is really low, and for the other it is really high. Thus everyone can endure what they want.

> Yeah, at some moment you have to respect the wishes of the patient I think, because someone can feel for themselves what the best thing is, what he can and cannot endure...

Disadvantages When it came to the disadvantages of euthanasia or of having a policy on euthanasia, participants were a little more varied in their responses. One participant felt it disadvantageous that euthanasia might be something which would be applied to easily.

> The disadvantage could be (pause) Where do you put the boundary? ...So that it's not just applied. Like for example, that it is done too soon.

For another participant, the possibility of having a decision about euthanasia made without taking part in the decision making process seemed disadvantages.

> I can imagine that people who are older, and who come to stay in a nursing home, that they are afraid that the physician will make a decision independently. Thus I can really imagine the anxiety, and I think that we should handle this very carefully.

This participant went on to discuss euthanasia declarations and the disadvantages of having and not having a declaration.

> The risk is that if you have a euthanasia declaration and you end up in coma, that they then perform euthanasia. The risk is also that with being in coma, that you could come out of it like a vegetable if you do not do it, and then I think, yeah, what would I want in this world [being] like this?

For one participant, their concern was not for themselves or other people who requested euthanasia but for the physician who carried out the request for euthanasia.

> A disadvantage I find is that physicians can be prosecuted. I'm not certain. A psychiatrist who helped someone (pause) and he [the psychiatrist] keeps going back and forth, first to Court and then the College of Physicians prosecutes him. Yeah, I find that an injustice, and then I think, what I have read about that man, everything was done so carefully and so weighed out. His patient was at wit's end. Yes, I find that a disadvantage, because I think that this man [the psychiatrist] has already had enough to deal with concerning his own emotions, his own I don't know what. That with this, that you would not have still another prosecution.

Future Influence Participants were asked what they felt the future influence of the Dutch policy on euthanasia would be for them. Some participants felt that this policy would have no affect on them in the future. Other participants felt that they themselves, could subscribe to euthanasia.

> For me, it only means an enormous peace. I have Multiple Sclerosis. I do not know what will happen. It could be very good, but it could also become very bad.
>
> ...when it is necessary, that also in my case, that it could be applied.

Some participants felt that if the policy was such that euthanasia would not be possible anymore, then they would resort to their own devices.

> Yeah, the policy now, it means that indeed (pause) that you are going to circumvent it. If from my perspective, it were to be necessary (pause) I would go myself, looking for a solution, because I would not like it if in the future I saw a need for it, and a physician wants to help me with it, that they are then prosecuted, because I feel that this person is then doing something as part of their profession, at my request. Yeah, and if we, both parties, agree to it, then you start circumventing the policy, as it is written today.

Abuse Concerns Some participants voiced concerns about the potential for abuse regarding euthanasia and the policy of euthanasia.

> Where are those boundaries? Where will those boundaries stay if you allow it, you know.
>
> I find personally, because then it [euthanasia] becomes legal, it can become a legal murder actually. You come to the doctor to say, "geez, my mother or so or your grandmother, she is not that well anymore and she has a lot of money which I want to have." Yeah, I think that this is possible.

For some participants, their concern lay with the physicians who had the authority to carry out an act of euthanasia, if they so desired.

> You know, there is still one more thing, because doctors, the medical world, physicians, even specialists, they are also not (pause) There are also rotten people in that group, also in the humanities, and I believe that they also said this in that program [*Death on Request*], but what is now already happening in practice, lethal injections with morphine (pause) [is that] Not true? And without consultation from another physician. That is now happening.
>
> ...if you are not able to communicate anymore, and you have really become a vegetable, that presently your physician will say, "geez, she is just laying in that bed and it is a shame about the money" I can imagine that for some people, that this would be very anxious.

As one participant described, with regards to the regulations concerning the policy of euthanasia:

> ...you can still fill things in a bit, with regards to how you want it. One person can, because of that, can allow something that might be illegal or can say, "I'm not going to touch this" and another person could say, "Yeah the law is such that if you handle it carefully, then you are free from any prosecution." So this person could in this sense, feel protected. For example, "Well I took into consideration all the rules, so I'm okay."

Safeguards Along with concerns about abuse, participants discussed some other issues which they felt needed to be safeguarded against.

> ...for someone who, for example, gets into an accident and who, because of that, breaks a leg or so (pause) Look, I don't think that this is a reason to say, "well boys, let's help with (pause)" I don't agree with that...
>
> You have to be very certain about it. A lot of people are not certain.

A suggestion that the processes be continually monitored was also offered.

> Yes, evaluation. Yes, in this respect, it is a good thing, and seeing that society does change, then you have to constantly evaluate to see if we are still doing it well. Are we doing it in the appropriate manner? Do we have to make changes?

Media When participants were asked to respond to the question concerning the influence of the media on their opinion on euthanasia, some felt that the media had no influence at all. People could agree or disagree with media presentation of euthanasia issues, but their opinion did not change. Some examples of media presentations were discussed. These examples exemplified participants' position on euthanasia.

> Then I think about that documentary, *Dood of Bezoek* [*Death on Request*] and the way I saw it there, then I think, yes, this is first class. ...I really enjoyed that documentary. I found it so honest, and that man was so prepared for it. ...It wasn't sensational or anything like that, it was really just very clear. ...I was also very moved by it, and yeah, that only makes me a big advocate of that in the sense that you can see how it could be, because that man would have otherwise choked to death at some point, and for him (pause) it was now enough.

Religion While interviewing participants in the Netherlands, the author came across some people who, while in support of euthanasia, were unwilling to be interviewed about it. When participants were asked about why some people might have difficulty with this topic, they responded that the topic itself and religion probably played a role.

> [It has to do with] death of course. ...I think that for a lot of people, religion also plays a role. I am also religious, but I am still very flexible with this.

> There are people who are very religious. Look, and now you are stepping on his toes and saying, "Yeah well, God does not allow that".

> I think that for some people it is easier than for others. If I look at my parents, they would not be so quick (pause) they would just say, "yeah, you're going to die when it is you time and if you have euthanasia performed, then it is still before your time."

Regardless of religion, autonomy was still an important factor in determining what decisions were made concerning one's self.

> I am of the opinion that it is a matter between God and myself, and if I think that I can answer to God, then actually it is of no concern to anyone else. Then the church

or the clergy or whoever, may not place judgment on that. They have nothing to do with that. That is mine.

Discussion

This study found that all participants supported euthanasia in situations of diminished quality of life based solely on physical suffering. Participants reasoned that if a patient was suffering or in great pain, then euthanasia would be preferred over life. This finding also is reported in the literature among patients with terminal illness, where the desire for death was found to be correlated with ratings of pain (Chochinove et al., 1995). Most participants felt that autonomy, the right to choose your own death, and futility of further medical treatment, were adequate reasons for requesting euthanasia. In addition, it was felt that a person who was suffering and who wanted to be assisted in death, should be given that right.

Some participants reasoned that euthanasia should be possible for people who are no longer contributing to society. These findings are supported by the literature which illustrates that one's perceived social ability appears to play a role in perceived quality of life and end of life decisions. For some of these participants, the issue of autonomy was not crucial when choosing for euthanasia given that the patient was not a functional member of society. In this context, the legal definition of euthanasia was extended to surrogate requests as well as self-determined requests. By legal definition, a surrogate may not make a request for euthanasia on someone's behalf. Some participants also felt that euthanasia was appropriate in situations that would allow the patient to die in a dignified manner. This response was given within the context of taking away the last few hour or days of life.

Participants did not limit their discussion of euthanasia to physical suffering. The possibility of requesting euthanasia for emotional suffering was as important to some participants. End-of-life decisions based on emotional suffering are being made in the Netherlands. The Chabot case was the first assisted suicide of a person with depression who did not exhibit any physical ailments. Given their own future prospects, some participants felt that even they could subscribe to euthanasia given the right circumstances. The knowledge that it was a possibility gave them the peace of mind to continue living.

Some participants reasoned that euthanasia was preferred over complete dependency on a third party. The literature seems to support this view, indicating that for people with physical disabilities, chronic, or terminal illness, dependency on others becomes a factor in making end of life decisions. By providing the means for people with disabilities to be more independent and have greater autonomy, their feelings of

dependency on family for care may decrease. This may reduce the number of end of life decisions which are based solely on the fear of being a burden to others.

Participants had both praise for, and concern about the act of euthanasia and its policy. They felt that those who suffered were most helped by euthanasia, and that everyone should have the right to choose when they wanted to die. Concerns with euthanasia or its policy focused on the possible risk of abuse. Abuse could stem from having euthanasia performed too soon, or having it performed against the wishes or without knowledge of the wishes of the patient. Additional concern was for the welfare of relatives and the physician upon completion of the act. Participants felt that relatives suffered because of their closeness with the patient. Paticipants felt that the physician suffered because of the risk of possible prosecution and the loss of his or her medical license. This fear of participants for the attending physician was also noted by Schaaf and Meyboom de Jong (1991), who interviewed relatives of people who had died as a result of euthanasia.

For participants, both the media and religion played a role in their perspectives on this topic. While some felt that their views on euthanasia were formed prior to outside influences, others were influenced by the Dutch media's portrayal of euthanasia, which was felt to be very positive. This claim may reflect participants' own positive view on the issue. Religion, on the other hand, was less influential on participants' views regarding euthanasia. Participants felt that while for others, it may be difficult to talk about this subject because of religion, for them it was once again an issue of autonomy.

As part of a broader study on euthanasia in the Netherlands, the consistency of responses by participants regarding their support for this practice, is shared by Dutch caregivers of people with disabilities. Similarities were found between the two groups concerning rationales for accepting euthanasia, views on surrogate requests for euthanasia, discussion of the appropriateness of specific cases of euthanasia, and ambivalence towards its practice given the potential for error or abuse (Lucardie & Sobsey, 1997).

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Conclusion

The goal of these studies was to identify participants' social realities concerning the act and policy of euthanasia in the Netherlands. The two studies presented similar findings of participants' perceptions of the Netherlands' policy on euthanasia. Both caregivers and people with disabilities voiced general support for the practice of euthanasia, with rationales based on quality of life. Autonomy, the right to make decisions concerning one's life, was also found to be a primary reason for the acceptance of the policy and practice of euthanasia. However, participants' discussion of the appropriateness of specific cases of euthanasia frequently focused on issues of futility of further medical treatment and the suffering of the patient. While autonomy was a conditional factor in some of these cases, in others it was not.

In these studies, the majority of participants did not distinguish between autonomous and surrogate requests for euthanasia. The policy guidelines however, only recognize autonomous requests for both euthanasia and assisted suicide. Yet these guidelines, which are in place to safeguard the practice of euthanasia and assisted suicide, have been shown to be inadequate to ensure personal control. Van der Maas, van Delden and Pijnenborg (1992) have reported on the practice of medical decisions concerning the end of life. Their research indicates life terminating acts without specific request of the patient accounts for approximately 0.8% of annual deaths in the Netherlands.

While generally supporting the policy of euthanasia, Dutch participants showed some ambivalence towards its practice given the possibility of abuse, and the uncertainties of the decision making process. Concern for the attending physician, who could face prosecution, was also voiced by both groups.

The implications of these findings suggest that the social realities of Dutch participants concerning euthanasia and its policy is different from the procedural guidelines as brought about by the Dutch Senate. The guidelines rule out any surrogate requests for euthanasia. Independent action by medical professionals is also deemed inappropriate. However, these guidelines continue to be challenged in Dutch courts of law, with physicians receiving acquittals for acting independently, and with parents requesting euthanasia on behalf of their children. Hence, the social realities of participants appear to be congruent with the evolution of the practice and legal acceptance of the practice of euthanasia and assisted suicide in the Netherlands. This wider application of this policy to situations which are by definition, not euthanasia nor assisted suicide, suggests a slippery slope.

In Canada, the Special Senate Committee on Euthanasia and Assisted Suicide recommended that nonvoluntary and voluntary euthanasia remain criminal offenses.

However, they also recommended that changes be made to the Criminal Code of Canada to allow for leniency in sentencing should elements of compassion or mercy be present as part of the act of euthanasia. It was suggested that this act could then fall under a separate category of offense termed compassionate homicide (Senate of Canada, 1995). This recommendation, if acted on, would establish a two-tiered sentencing system whereby the act of taking a life could be justified, if some degree of compassion could be demonstrated by the perpetrator. Those people then most at risk for having nonvoluntary euthanasia performed on them would be persons who are deemed to be suffering and are unable to communicate their wishes. If their caregivers felt that it would be more merciful to take the life of their charges than to allow them to continue living, the courts could then possibly recognize these actions as being less serious in nature than the taking of a life of someone who was not deemed to be suffering. The subjectivity in determining if and how much a person might be suffering would place certain people in our society at greater risk for having nonvoluntary euthanasia performed on them.

In the Netherlands, the policies which are in place concerning end of life decisions continue to be challenged in the courts and other levels of government, and have resulted in changes. In 1995, a Dutch euthanasia defense court case resulted in the acquittal of a physician, involved Dr. Henk Prins, a gynecologist. Dr. Prins had previously been found guilty of murder in the case of a 3 day old infant girl with multiple disabilities who was reported to be in pain. A request for euthanasia was brought forward by the infant's parents. The court ruled that Dr. Prins acted in accordance with responsible medical opinion and medical ethical norm, in carrying out the parents' wishes (Sheldon, 1995). On March 25, 1997, Dutch prosecutors from the city of Leeuwarden charged Dr. Sippe Schat with murder, for ignoring the guidelines concerning the practice of euthanasia. Dr. Schat administered a fatal dose of insulin to a 72-year-old woman who was dying of cancer. Dr. Schat did not obtain written proof of his patient's wishes, nor did he obtain a second opinion. In addition, he reported the woman's death to be from natural causes (Corder, 1997; Sheldon, 1997a). Sheldon (1997b) reports that the Dutch cabinet has recently announced plans allowing physicians who perform euthanasia or assisted suicide to report to regional committees consisting of physicians, lawyers and ethicists. Currently, any physician who performs these acts has to report to the local magistrate who decides on whether or not to prosecute.

In other countries which have passed or voted on laws accepting physician assisted suicide, changes are also being seen regarding the implementation of those laws. On July, 1996, the Northern Territories in Australia legalized the practice of physician assisted suicide. On March, 1997, this law was overturned by the Senate of Australia. While the

law was in affect, four people had been assisted in suicide (Thornhill, 1997). In the United States, Mechkler (1997) reports that the Supreme Court is currently examining cases of assisted suicide from New York and Washington state. Regardless of the ruling in these cases, a bill has been brought forward to ban any Federal funding of physician assisted suicide, should this act become accepted.

Supporters of euthanasia and assisted suicide have previously made gains in the courts and among legislators concerning these acts, especially in the Netherlands, where the greater application of the Dutch policy concerning euthanasia and assisted suicide is being seen today. However, recent repeals of laws concerning physician assisted suicide seem to suggest that in other countries, opponents of this act are gaining momentum. The direction this debate will continue, can only be seen in time. It is hoped that the information contained in these two studies will contribute to the ongoing debate.

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INTERVIEW PROTOCOL
Euthanasie & Assisted Suicide Survey

Mijn naam is Richard Lucardie. Ik ben met een onderzoek bezig voor de universiteit van Alberta in Canada. Canada overweegt momenteel euthanasie en de hiermee in verband zijnde voorschriften voor begeleiding over te nemen op dezelfde basis als het in Nederland wordt toegepast. Wij willen graag meer weten hoe deze voorschriften een effect hebben op de Nederlanders, zodat het ons kan helpen in onze planning.

Uw deelname is op volledig vrijwillige basis. Als U niet aan dit onderzoek wilt deelnemen, kunt U het ten alle tijde zeggen en de vragenstelling houdt hierbij op. Zelfs als de vragenstelling geeindigd is, heeft U het recht om te zeggen het niet te gebruiken.

Als U aan het onderzoek wilt deelnemen, dan zou ik U enkele vragen willen stellen, die ongeveer twintig tot dertig minuten in beslag zullen nemen. Uw antwoorden worden getaped en later voor analyses uitgetypt.

Deze antwoorden zijn strikt vertrouwelijk. Ik zal de tape overspoelen nadat de antwoorden zijn uitgewerkt. De antwoorden zullen gescheiden worden van Uw toestemmingsformulier om zodoende Uw privacy veilig te stellen. Met Uw toestemming zullen wij bepaalde gedeelten van het interview gebruiken om het resultaat van onze studie te illustreren. Als U vragen heeft, dan mag U die rustig stellen voordat we beginnen.

Gaat U akkoord met het interview? ___ Ja ___ Neen

Mogen wij bepaalde aanhalingen van dit interview gebruiken?
___ Ja ___ Neen

Wat is Uw naam? _____

Uw handtekening. _____

Richard Lucardie, Research Associate

Professor Dick Sobsey, Principal Researcher
Developmental Disabilities Centre
University of Alberta
Edmonton, Alberta T6G 2G5 Canada
1-403-492-3755

INTERVIEW PROTOCOL

Euthanasia & Assisted Suicide Survey

My name is Richard Lucardie. I am currently doing research for the University Alberta in Canada. Canada is momentarily considering the policy of euthanasia as it is written in the Netherlands. To help us with our planning, we would like to know what affect the Dutch policy on euthanasia has on people in the Netherlands.

Your participation in this study is completely voluntary. If you do not wish to participate, then you may say so at any time and the questions will discontinue. Even upon completion of the interview, you retain the right to say that you would not like your responses used.

If you wish to participate with this study, then I will ask you several questions which will take about twenty to thirty minutes of your time. Your responses will be tape recorded, and will later be typed out for analysis.

Your responses are in strict confidentiality. I will erase the tape recording as soon as the responses are analyzed. The responses will be separated from you consent form in order to protect your privacy. With your consent, we will be using certain parts of the interview to illustrate the results of our study. If you have any questions, please do not hesitate to pose them before we begin.

Do you agree to be interviewed? ___ Yes ___ No

May we use certain quotations of this interview for our study?
___ Yes ___ No

What is your name? _____

Signature: _____

Richard Lucardie, Research Associate

Professor Dick Sobsey, Principal Researcher
Developmental Disabilities Centre
University of Alberta
Edmonton, Alberta T6G 2G5 Canada
1-403-492-3755

VRAAGEN VOOR VERZORGERS

1. Wat is Uw mening over euthanasie?

2. Wat voor invloed hebben de huidige voorschriften op euthanasie en de hiermee verband houdende begeleiding gehad op U en de bewoners?

3. Wat voor invloed zullen deze voorschriften in de toekomst op U en de bewoners hebben?

4. Hoe denkt U over de voor -en nadelen van deze voorschriften?

5. Wie zijn hiermee geholpen? Wie hebben er onder geleden?

6. Wat voor invloed heeft de media op Uw mening op euthanasie?

7. Waarom denkt U dat het soms moeilijk is for sommige mensen om over euthanasie te praaten?

QUESTIONS FOR CAREGIVERS

1. What is your opinion about euthanasia?

2. What influence has the Dutch policy on euthanasia had on you and the residents you care for?

3. What influence will this policy have on you and the residents in the future?

4. What do you feel are the advantages and disadvantages of having a policy on euthanasia?

5. Who have been helped by this? Who have suffered because of this?

6. What affect does the media have on your opinion on euthanasia?

7. Why do you think that it is sometimes difficult for people to talk about euthanasia?

VRAAGEN OVER EUTHANASIE

1. Wat is Uw mening over euthanasie?

2. Wat voor invloed hebben de huidige voorschriften op euthanasie en de hiermee verband houdende begeleiding gehad op U en Uw familie?

3. Wat voor invloed zullen deze voorschriften in de toekomst op U hebben?

4. Hoe denkt U over de voor -en nadelen van deze voorschriften?

5. Wie zijn hiermee geholpen? Wie hebben er onder geleden?

6. Wat voor invloed heeft de media op Uw mening op euthanasie?

7. Waarom denkt U dat het soms moeilijk is for sommige mensen om over euthanasie te praaten?

QUESTIONS ABOUT EUTHANASIA

1. What is your opinion about euthanasia?

2. What influence has the Dutch policy on euthanasia had on you and your family?

3. What influence will this policy have on you in the future?

4. What do you feel are the advantages and disadvantages of having euthanasia, or a policy on euthanasia?

5. Who have been helped by this? Who have suffered because of this?

6. What affect does the media have on your opinion on euthanasia?

7. Why do you think that it is sometimes difficult for people to talk about euthanasia?